

ORIGINAL RESEARCH ARTICLE

A Qualitative Analysis of the Barriers and Facilitators to Receiving Care in a Prevention of Mother-to-Child Program in Nkhoma, Malawi

Ngozi D. Iroezi^{*1}, Deborah Mindry², Paul Kawale³, Grace Chikowi³, Perry A. Jansen⁴ and Risa M. Hoffman⁵

¹Department of Medicine, David Geffen School of Medicine at UCLA, Olive View-UCLA Medical Center, 14445 Olive View Drive, 2B-182, Sylmar, California, CA 91324. ²Center for Culture and Health, Department of Psychiatry and Behavioral Sciences, Semel Institute, UCLA, 760 Westwood Plaza, Box 62, Los Angeles, CA 90024. ³Nkhoma Hospital, Private Bag 206, Lilongwe, Malawi. ⁴Partners in Hope Medical Center, PO Box 302, Lilongwe, Malawi. ⁵Department of Medicine and Division of Infectious Diseases, David Geffen School of Medicine at UCLA, 10833 Le Conte Ave 37-121 CHS, Los Angeles, California 90095.

***For correspondence:** email:ngozi.ucla@gmail.com; Phone: 818-364-3205,

Abstract

Prior to 2011, uptake of PMTCT in Malawi remained low despite increased access to antiretrovirals. We sought to understand barriers to PMTCT in rural Malawi. Twenty-two HIV-infected pregnant and postpartum women in PMTCT programs were interviewed in Nkhoma, Malawi, between April-May 2010. All women were staged by WHO criteria or CD4 count as ineligible for three-drug treatment by Malawi's HIV Guidelines at the time. The median age was 26 years (range 22-39) and 77% were married. Barriers to accessing PMTCT care included transportation to clinic, stigma in the community leading to avoidance of HIV disclosure, food insecurity, and providers' attitudes towards HIV-infected pregnant women. Given Malawi's transition to Option B+ for PMTCT in which women are initiated on antiretroviral therapy (ART) during pregnancy and continued for life, strategies to improve access and retention will need to address barriers and incorporate facilitators that motivate and retain women in HIV care. *Afr J Reprod Health* 2013 (Special Edition); 17[4]: 118-129.

Keywords: HIV/AIDS, Malawi, maternal health, prevention of mother-to-child transmission

Résumé

Avant 2011, l'adoption de la PTME au Malawi est restée faible malgré un accès accru aux antirétroviraux. Nous avons cherché à comprendre les obstacles à la PTME dans les régions rurales du Malawi. Vingt-deux femmes enceintes et les femmes du post-partum qui sont infectées par le VIH et qui suivaient les programmes de PTME ont été interrogées à Nkhoma, Malawi, entre avril et mai 2010. Toutes les femmes ont été mises en scène par des critères de l'OMS ou des CD4 qui comptent comme inéligible pour un traitement de trois médicaments par les lignes directrices du VIH au Malawi à l'époque. L'âge médian était de 26 ans (extrêmes: 22-39) et 77 % étaient mariés. Les obstacles à l'accès aux soins de la PTME comprennent le transport à la clinique, la stigmatisation dans la communauté, ce qui mène à l'évitement de la divulgation, l'insécurité alimentaire et les attitudes des prestataires envers les femmes enceintes infectées par le VIH. Compte tenu de la transition du Malawi vers l'Option B+ de la PTME dans laquelle les femmes sont initiées à la thérapie antirétrovirale (ART) au cours de la grossesse et qui continué à vie, il faudra que des stratégies pour améliorer l'accès et la rétention surmontent les obstacles et à intégrer les animateurs qui motivent et retiennent les femmes en matière de soins du VIH. *Afr J Reprod Health* 2013 (Edition Spéciale); 17[4]: 118-129.

Mots-clés: VIH/SIDA, Malawi, santé maternelle, prévention de la transmission de la mère à l'enfant

Introduction

The use of antiretrovirals (ARVs) to prevent mother-to-child transmission (MTCT) of HIV has averted approximately 269,000 infections in the 25

highest burden countries since the inception of these programs in approximately 2000¹. Despite the success of ARVs in preventing MTCT, it is estimated that worldwide approximately 370,000

children were infected with HIV in 2009, with 90% of those infections the result of MTCT². Studies have shown that ARVs in resource poor settings can reduce the rates of MTCT significantly³⁻⁶. Some studies show a decrease of MTCT from approximately 25% with no treatment to 2% with single dose or short course combination regimens¹. It is clear that ARVs for pregnant women are crucial for decreasing transmission of HIV to the unborn child. However, there remain challenges in the implementation of prevention of mother-to-child transmission (PMTCT) programs.

Malawi is a poor country in sub-Saharan Africa, with a population of approximately 15 million people, and an HIV prevalence of 12%⁷. Transmission from mother-to-child is the second most common cause of HIV-infection in Malawi. In 2004, in order to combat this issue, Malawi initiated wide-scale PMTCT programs. As of 2009, 38% of eligible pregnant women were receiving ARVs for MTCT⁷. Despite the efforts to increase access to PMTCT programs, coverage during that period of time remained low. Reasons for low rates of women initiating ARVs for prevention of MTCT remain unclear, but have been attributed to poor access to care, particularly for rural women, late presentation for care in pregnancy, and lack of interface with the health system during pregnancy and delivery due to use of traditional birth attendants who are not trained in the delivery of ARVs for MTCT⁸⁻¹⁰.

We performed a qualitative study with HIV-infected women who were either pregnant or were recently pregnant and involved in a PMTCT program in a rural hospital and two affiliated health clinics to learn about barriers and facilitators to accessing and being retained in the program through delivery. All women included were staged by either WHO criteria or CD4 as ineligible for three-drug antiretroviral therapy (ART) by Malawi's current guideline at the time under study (250 cells/mm³).

The goal of this study was to identify interventions to improve access to care for women not qualifying for longitudinal follow-up in ART clinics. Malawi has recently implemented a new program for PMTCT that includes providing ART for life to all HIV-infected pregnant and

breastfeeding women, regardless of CD4 cell count (Option B+)¹¹. In Zambia, a pilot study has shown the effectiveness of option B in decreasing HIV transmission to infants¹². The use of the Option B+ strategy in Malawi can greatly reduce the number of perinatal and breastfeeding HIV transmissions, but has presented new challenges to both improve access to care during pregnancy, as well as to improve retention in care long-term¹³. To achieve success within the Option B+ framework, it will be necessary to address the barriers and facilitators to HIV care for pregnant and postpartum women in Malawi.

Methods

This study was performed in three rural sites in Nkhoma, central Malawi between April and May 2010. The participating sites were Nkhoma Hospital and two referring health clinics, Mvera and Mphunzi located approximately, 231 km and 214 km from Nkhoma Hospital respectively. HIV-infected pregnant and postpartum women were approached and invited to participate in the study when they came for their antenatal clinic visit or an HIV support group. A total of 22 HIV-infected women agreed to participate and were interviewed. All women included were staged by either WHO criteria or CD4 cell count as ineligible for ART by Malawi's current National HIV Treatment at the time under study (250 cells/mm³) and therefore referred for PMTCT using short course combination ARVs, with maternal therapy started during pregnancy and stopped after delivery. Informed consent was obtained from all participants. Ethical approval for the study was granted by the Malawi National Health Sciences Research Committee and a human subject exemption was granted by the UCLA Internal Review Board.

A standardized questionnaire had been designed by a University of California, Los Angeles (UCLA) team comprising of physicians involved in HIV care and postdoctoral researchers (Table 1). The questionnaire was being pilot tested for future research and given the small scale of the study was not tested for reliability. However, it was presented to physicians, public health specialists, researchers, and nurses in

Malawi and further modified to be appropriate for the clinical and cultural setting. Following review, the instrument was tested with women in rural Malawi and further modified before use in the study.

Patients participated in in-depth, structured interviews conducted in Chichewa. If the participant agreed, responses were audio recorded. Questions were asked about the following general subject areas: knowledge about PMTCT, transportation, social support, stigma, family planning, and knowledge about infant HIV testing.

Recorded interviews were reviewed by a second Chichewa native speaker, translated, and transcribed in English. After transcription, the interviews were reviewed and coded according to recurring themes that came up in the interview with regards to facilitators and barriers to PMTCT care at Nkhoma Hospital. The coding scheme was externally reviewed by colleagues familiar with the setting and with expertise in qualitative data analysis. The major themes that emerged from coding were analyzed subsequently and categorized into sub themes.

Table 1: Interview Instrument

OPENING QUESTIONS	You are here to receive medicine to help prevent your baby from getting infected with HIV. Tell me about what led to you coming here for this care. (Probe: Were you sent here by another person? If so, who or by what clinic?)
KNOWLEDGE ABOUT PMTCT	Tell me what your understanding is of these treatments or medicines? (Probe: What do you think they will do?) (Probe: What do you want them to do?) (Probe: How can they help you? Do you think these medicines are effective? Why do you think so?) (Probe: What have you heard about them from other people?) Are you taking any HIV medicines right now? IF YES: How often do you miss doses? (Probe: once per week? twice per week?) Could you please tell me what you know of how HIV is transmitted?
BARRIERS AND FACILITATORS TO GET TO THE PMTCT CLINIC	Tell me what your plans and thoughts are about returning to this PMTCT clinic during the pregnancy. (Probe: What did the [counselor/hcw] tell you about how often you are supposed to come for clinic visits?) IF YES: Can you tell me when you are supposed to return for your next visit? IF NO: Did anyone ever talk to you about this? Who? Do you think you will come back to this clinic? Why or why not? Does anything make it hard for you to come back to this clinic? (Probe: too far to travel to get the care you needed?) (Probe: cost too much?) (Probe: you feel too embarrassed to talk about your problems?) (Probe: do the medicines make you feel sick so that you don't want to take them anymore?) (Probe: was it because you couldn't take time away from work or taking care of children, or other household responsibilities?) (Probe: were you afraid that other people (friends, family) might find out your HIV status?) (Probe: were you afraid that others might find out, provider being rude / not supportive?) (Probe: because the health care worker was not supportive (did not explain things, did not help you in the way you wanted or expected?) What would make it easier for you to come back again? Sometimes women like you, who are pregnant and taking medicines to prevent HIV in the baby, have a person who they choose that accompanies them to clinic visits, helps them remember to take their medicines, and helps them remember all the things they need to do to stay healthy. This person may be a friend, a family member, or anyone else that the woman chooses from their community. Would you like to have someone like this to help you? (Probe: Why or why not? Would you be afraid about this person knowing about your HIV? Would you be concerned it's not helpful?) Who among your husband, family or friends knows your HIV status? What does your (husband, family, friends) think about your receiving these medicines?

EARLY INFANT DIAGNOSIS QUESTIONS	<p>(Probe: Do they agree with your getting these medicines? Or do they disagree with it? Why?)</p> <p>Can you tell me what you know about health services for your baby after your child is born? (Probe: Has a healthcare worker or anyone else told you about returning for infant testing? Did they tell you when to return for infant testing?) (Probe: Have you ever used PMTCT or infant HIV testing when you were pregnant before?)</p> <p>What might make it hard for you to come back to have your baby HIV tested? (Probe: fear of learning the baby is HIV+? Difficulty finding time because of things to do at home such as cooking, laundry, taking care of new baby and other children? Too far to come to this clinic? Too expensive to pay for transport or such as bicycle taxi? Cost of clinic visit?)</p>
ART QUESTIONS	<p>What would make it easier for you to come back? (Probe: Would having it in another location closer to your home/village?)</p> <p>Can you tell me what you know about health services for yourself after your child is born? (Probe: Available treatments that can treat HIV and keep you healthy now that you are HIV+? Do you think they are effective?)</p> <p>Do you know where to go (which clinic) to get HIV medicines? Will anything make it hard for you to come back to get these medicines? (Probe: fear that if you go to the clinic people will know you have HIV? (Probe: cost, distant to clinic? cost of transportation to clinic?) (Probe: Available treatments that can help to prevent AIDS in your child if she is infected?)</p> <p>What would make it easier for you to come back to clinic to keep getting care for HIV, including medications? (Probe: Would having it in another location closer to your home?)</p>
PRE-ART QUESTIONS	<p>Tell me what your plans and thoughts are about returning to the HIV clinic after your baby is born. (Probe: Has your health care provider talked with you about what type of health care you will need for your HIV infection after your baby is born? What did the [counselor/hcw] tell you about how often you are supposed to come for clinic visits?)</p>
PREGNANCY AND FAMILY PLANNING	<p>Do you think you <i>will</i> come back to this clinic? Why or why not?</p> <p>When you first learned that you were HIV-positive, did your attitude towards having further children change?</p> <p>Did this attitude change when you learned that you could take measures to give birth to a healthy child?</p> <p>Did this attitude change when you learned that you could take measures to give birth to a healthy child?</p>
DEMOGRAPHICS	<p>Do you know where to go if you wanted family planning services? Have you ever used them?</p> <p>How old are you? (READ CATEGORIES)</p> <p>18–24.....1</p> <p>25–29.....2</p> <p>30–39.....3</p> <p>40–44.....4</p> <p>45–49.....5</p> <p>50–59.....6</p> <p>60–64.....7</p> <p>65 OR OLDER.....8</p> <p>REFUSED/DK.....9</p> <p>Are you currently...?</p> <p>Married.....1</p> <p>Not married but have a partner.....2</p> <p>Separated/divorced.....3</p> <p>Widowed.....4</p> <p>Never married.....5</p> <p>Do you have any children 17 years of age or younger living with you?</p> <p>IF YES: How many?</p> <p>How did you get to this clinic?</p> <p>Walk.....1</p> <p>Bus.....2</p> <p>MiniBus.....3</p>

	Bicycle taxi.....4
	Car.....5
	What is the cost (one-way) of travelling to this clinic?
	<200 Kwacha.....1
	200-500 Kwacha.....2
	>500 Kwacha.....3
	How long does it take you to get to the clinic or hospital nearest to where you live?
	30 minutes or less.....1
	30 minutes to 1 hour.....2
	1-2 hours.....3
	>2 hours.....4
CLOSING	These are all the questions I have. Thank you very much for answering our questions. Do you have any questions, or comments you would like to make about what we talked about? Is there anything else would you like to tell us?

Results

Characteristics of the Study Population

A total of 22 women were interviewed with 68% (N=15) pregnant at the time of the interview. The remainder, 31% (N=7), were postpartum and had delivered within the previous six months, having received antenatal care at Nkhoma or one of the referring health centers included in the study. The median number of live children per woman was four (range 0-6). The median duration of commute to Nkhoma Hospital for PMTCT was two hours and the majority of these women traveled by foot. The median age of the women interviewed was 26 years (range 22-39 years old) and 77% of the women were married. A total of 15 women were recruited from Nkhoma Hospital, three women were from the Dowa site and four women were from the Mvera site.

Barriers to PMTCT Care

Transportation to the hospital or health center sites was the most common barrier to accessing PMTCT services identified in the study. Ninety percent (N=19) of the women spoke of transportation problems, specifically the distance needed to travel to the PMTCT program and the cost of transport. Nine women lived at least two hours walking distance from the hospital. A 24-year-old mother of two stated that, *'There are taxis or motorcycle, or cars, but because we do not have money, we just walk'* (May 5, 2010). Some chose to walk half the distance to the PMTCT site and then take a bus, in order to save money. A 39-year-old pregnant mother of six said:

'Most of the times we just walk from the village to here but sometimes if you have a little bit of money, you get on the bicycle taxi and from where we come from, since it's far, the bicycle taxis are 200 kwacha. Some charge up to 250 kwacha. So, we think that it is better just to walk' (April 20, 2010).

The average cost for transportation was reported by women to be approximately 200 kwacha, close to the average cost of food for an adult for one day. Of the 22 women interviewed, only one owned a bicycle. One 31-year-old pregnant participant did state that the cost of transportation prevented her from coming to the PMTCT clinic on several occasions:

'It sometimes happens that we have no money and when you think of the distance it's very far and the distance coming in is very far and that makes me say that I am not going. So as a result, I just sit at home' (April 28, 2010).

Ten women stated that they would be willing to go to a health center if it was closer. However among those who did have a health center close by their village, they all chose to come to the main hospital in Nkhoma Hospital because they felt it had better resources. A 25-year-old mother of four stated:

'If there was a mobile clinic nearby, I would still want to bring my child here (to Nkhoma Hospital) because it would still be different and I would prefer to bring my child here, even if there was a mobile clinic nearby our home because it is

different. I feel the hospital here is better and I feel that this is where I can get adequate help' (April 14, 2010).

In some cases they also noted that ARVs and CD4 testing were not available at the local health centers. A 39-year-old mother of four reported that, *'The reason why I come here [Nkhoma Hospital] and not there is because there they have not started distributing ARVs so I have to come here to come and access that treatment' (April 20, 2010).*

Another major barrier to accessing care was difficult interactions with medical staff in the antenatal clinic. Twenty percent of women spoke of experiencing problems during their interaction with the medical personnel. Others had not had any direct experiences, but did report hearing about cases from other women. The scenarios described occurred mostly during labor and delivery. However, women also reported harsh treatment when coming to collect ARVs. A 24-year-old pregnant mother of four spoke of a past experience at the antenatal clinic. She said,

'For example, when you come for the antenatal clinic, the way they treat us, it is really bad. Sometimes when they are examining us, they are very rough, in such a way that it is painful, we feel pain. And when it comes for the time to deliver, they are so rude and very harsh, they shout at us instead of just telling us nicely what to do. They shout at us and tell us, sit there, it is not yet time, just sit. When you yourself know that your time has come for you to give birth' (April 28, 2010).

The above experience was not specifically discussed as related to HIV status; however, a few women indicated that difficult interactions were felt to be due to HIV status. A 33-year-old pregnant mother of four reported that, *'There is a doctor by the name of --- who when you are in labor and when an HIV person goes there in labor, they don't receive that patient well' (April 21, 2010).* Some women reported harsh words or treatment when they come to collect their medications. The 33-year-old pregnant mother of four above stated:

'The insult, that I know there is somebody who treats us very harshly here, especially a man by the name of ---. When you come to get medication here, before he gives you the medication, he will rain insults at you first and then sometimes he just leaves you there on the queue and goes to walk around in the hospital grounds and he comes whenever he feels like. Now is the time to go and give those people medication. That's when he comes and gives you the medication – in his own time' (April 21, 2010).

Inability to obtain a CD4 cell count was noted as a barrier to timely care for women seeking treatment for PMTCT. Many women spoke of being told to come back repeatedly to have a CD4 blood test, only to find the test unavailable, due to lack of functional equipment or reagent shortages at the hospital site. Additionally, on certain occasions, blood drawn for CD4 counts would be sent to distant sites for processing, with slow turnaround (weeks to months) hindering the delivery of ARVs in a timely manner. Ten out of 22 women had never had a CD4 count since their diagnosis.

Stigma was another recurring theme participants reported as a barrier to care. Fifty-six percent (N=12) of the women reported being stigmatized in their communities by individuals outside of their family. Most of the stigma was described as open derision, avoidance, or gossip. For example a 23-year-old mother of two reported: *'Someone once said to me that, "Get away from here, you who takes ARVs"' (April 23 2010).* A 34-year-old pregnant mother of one also reported her experiences: *'They talk about me, they point fingers at me and say, "look at her, she has the virus," and they talk about me – not small talk they really talk about me' (April, 30, 2010).* Another 23-year-old mother of two reported,

'Sometimes we are insulted. They say, "You people with HIV, you are here just because of the medication. I think the hospital should just stop giving out ARVs so that all of you can just die." These are some of the things which they say about us' (April 16, 2010).

In addition, 20% (N=4) of women interviewed from different villages reported that they were

deprived of community fertilizer because they were HIV-positive. A 24-year-old woman in her first pregnancy stated:

'Like this last year, they were giving out coupons, my name was on the list but they did not give me the coupons. They told me that the fertilizer was not enough; there was a shortage of fertilizer but I knew that was not the case and I told them that it is fine; God is the one who is in control of everything. They said I would not be able to cultivate my land' (May 4, 2010).

Another 26-year-old pregnant mother of four said, *'Yes, in my home village, they don't give us any of the fertilizer coupons. We have passed through a lot. We have been insulted and discriminated against' (April 16, 2010).* A 20-year-old pregnant mother with six children (three of whom were deceased) stated that, *'The only stigma that I can think of is the issue of fertilizer coupons. When they come, they do not give any to us who are HIV-positive' (April 15, 2010).*

Facilitators to accessing PMTCT care

One of the major facilitators to access and retention in care was the excellent quality of education and support services provided by the PMTCT program at Nkhoma Hospital. Women were provided with counseling and had a clear understanding of the timing of subsequent follow-up visits, the schedule for support groups, and the availability of infant testing services. A 33-year-old woman reported the following information about follow-up visits: *'The doctors write the date in our health passports but they also tell it to us verbally' (April 21, 2010).* With regards to counseling 81% (N=18) of women recalled being counseled when first diagnosed with HIV while pregnant. Two-thirds (N=14) of the women had a good understanding of the purpose of the ARVs and understood that they had to take it on a daily basis. A 24-year-old mother of two, when asked if it was possible that she ever missed a dose of her ARVs, replied, *'No it's not possible. No, I drink it first thing in the morning before I leave and if I am going to spend the night there I carry the*

medication' (May 5, 2010). Out of the 22 women interviewed only three admitted to ever missing a dose.

Two-thirds of women were in support groups either through the hospital or in their villages. Women who participated in support groups for more than a year had better knowledge, less misinformation and myths about how HIV is transmitted and more accurate information about how to prevent mother-to-child transmission. For example, over ninety percent of the women in support groups understood that their infants would require early testing after birth to determine if the infant had become HIV-infected during pregnancy or delivery.

Infant testing was also a motivation that facilitated retention in the MTCT clinic program. A 23-year-old mother of two stated: *'No there was nothing that made it difficult to come with the child for the PMTCT and to come for testing for the child. I followed the PMTCT procedures. I followed all of them with the last child' (April 23, 2010).* Another 26-year-old mother of four stated: *'I came because I wanted to provide good care for my baby' (May 5, 2010).*

HIV disclosure appears to be another important facilitator, improving women's ability to seek care at a program for prevention of MTCT. Disclosure of status removed the element of secrecy and these women reported being more likely to show up for their appointments without fear of being seen at the PMTCT clinic. A 34-year-old pregnant mother with one child stated: *'Other people come secretly to come and collect medication so that other people don't know. But as for me, I have disclosed my status, so everybody knows' (April 30, 2010).* HIV disclosure also facilitates care by allowing for family support. Sixty percent of women interviewed reported receiving support from their husbands in the form of reminders to take ARVs, accompaniment to clinic visits, or moral support. Ten women reported that their husbands accompanied them to clinic visits. A 23-year-old mother of two explained the support she received from her husband:

'My husband, sometimes when they insult me, I go home in tears and my husband encourages me and tells me that, "Don't

worry. You should just pray to God. He is the one who answers everything. And besides, those people that were talking about you, they have never been tested and they don't know what their status is. The only person who can know their status is someone who has gone and gotten tested so don't mind them. Let them talk. Don't mind them''' (April 23, 2010).

Access to food and food support was also found to be an important facilitator to PMTCT care. Many of the women reported receiving aid in the form of food and food supplements for their infants and/or money from support groups when they came for meetings. They also had access to a garden near the hospital and 20% of them voiced interest in having a garden closer to their homes. A 26-year-old mother of two stated:

'The other thing where I think maybe the hospital can help us is that, for example, we have a garden and now there's maize, but our homes are very far away. And we are asking that maybe in the future, we can help with the garden, but maybe we can also be assisted to have gardens in our home villages so that we don't have to carry anything from here because where we come from it's very far' (April 20, 2010).

In addition, five women stated that receiving fertilizer would be helpful to ensure an abundant harvest to feed themselves and their families. Some women were sole supporters of their family. Approximately 15% spoke of their husband leaving them or marrying another wife when they were diagnosed with HIV. These women expressed that support with food and or nutritional information would provide a clear motivation to stay connected to the clinic during pregnancy and postpartum.

Discussion

This study aimed to evaluate the predominant barriers and facilitators to participating in a PMTCT program in rural Malawi. The initiation

of PMTCT has been an important step in curtailing HIV infections in infants. However, improving uptake and adherence to care still remains a significant challenge in Malawi and similar resource-poor settings. Several publications, including from Malawi, have reported an antenatal care dropout rate of greater than 50% by the 36th week of pregnancy^{7,9,14,15}. Malawi has recently transitioned to making ART available for all HIV-positive pregnant and breastfeeding women for life as part of their new Option B+ program. Understanding access to and retention in care will improve participation and ensure optimal outcomes for women and their infants.

Barriers to PMTCT Programs

Transportation

Women reported struggling with the long distances to travel to a health facility. The average walking distance to the nearest hospital in our study was about two hours and many chose to walk, as they could not afford to pay for transportation. In many remote areas, public transport was not available even when desired. Other studies have also reported transportation to be a major hindrance to accessing care^{16,17}. An antenatal program in the Thyolo district in rural Malawi identified lack of transportation as a barrier to accessing PMTCT care and a reason for loss to follow up from the PMTCT program⁹. The high dropout rate early in pregnancy resulted in women not receiving ART later during pregnancy. There is a need for an increased number of health facilities that are in close proximity to or are in rural communities. The implementation of the Option B+ program in Malawi has resulted in decentralization of ART and more studies are needed on whether the transportation barriers have been adequately addressed with this policy change. Interestingly, in many cases, patients chose to go to a distant hospital even if there was a clinic nearby and reported that this was due to a lack of available resources for HIV care at nearby clinics. Therefore, in addition to increasing the number of health centers available to communities, it will also be necessary to ensure adequate resources and capacity in these clinics.

Stigma

In our study, stigma was defined as harsh words and ridicule by members of women's communities. Stigma has been shown to decrease HIV testing, disclosure, uptake of PMTCT, and subsequent adherence and retention in care^{8,18-20}. Our study also showed that stigma was strongly tied to food insecurity. In those communities where leaders selectively refused to give fertilizer to HIV-positive community members, HIV-positive women ran the risk of poor or no crops at the end of the farming season. Many women may choose not to disclose their HIV status, or avoid HIV testing, in order to continue to receive agricultural support from the community. In order to help reduce stigma in rural Malawi, it will be important to engage community leaders, to improve knowledge in communities, and to build advocacy for and by women living with HIV.

Provider Attitudes

Difficult interactions between HIV-positive women and medical staff were another deterrent to accessing care. Several women reported being hesitant about coming to the hospital, especially for delivery, because of poor treatment they have received in the past or heard about through HIV-positive friends and/or family members. Difficult interactions may deter women who already have multiple obstacles to accessing care. This was noted in a Ugandan community where poor treatment of HIV-infected women was noted as a barrier to ART¹⁷. A recent study from sub-Saharan Africa reported that disengagement from care among HIV-positive individuals was associated with dissatisfaction with the care received at the clinic, including harsh treatment from health workers, with patients reporting feeling hurt, humiliated, and angry, and reluctant to return to care²¹. Critical to the success of PMTCT programs will be efforts at addressing provider attitudes towards HIV-infected patients. Solutions should include implementing medical provider training, tools to enhance sensitivity to the women's needs, increased staffing, and encouraging dialogue between the medical personnel and the community²².

Helping women access PMTCT: Current and potential facilitators

High quality education and clarity about follow-up and knowledge of methods to prevent MTCT was clearly a facilitator reported by women in this study. Women engaged in PMTCT at Nkhoma understood the treatment plan and reported that they were given clear instructions for follow up and a physical reminder of appointments in their health passports. Among women interviewed, knowing that their infants could have the chance to live an HIV-negative life was also a great motivator for the women to continue to come for follow-up care, especially postpartum. Other studies have also shown that the desire to have an HIV-negative baby has been a motivator for attending PMTCT programs¹⁰. As part of Option B+, it will be important to continue to link the infant's and mother's health in a way that motivates women to continue to access care both during pregnancy and beyond.

In addition to knowledge being an important facilitator, women engaged in care reported great benefit from nutrition resources, including a demonstration garden to help develop agricultural skills. Studies have shown improved nutritional status of HIV-positive women and children following implementation of gardening services or nutrition resources in the home^{23,24}. Further studies are needed to know if these programs can truly increase uptake and adherence to HIV care for pregnant women and to measure the cost of such programs, to determine the feasibility of scale-up as part of HIV care.

Study Weaknesses

The information reported in this study was originally collected as part of a small quality improvement project, and therefore detailed information on participants is lacking. It would be helpful to have additional demographic and clinical information (CD4 cell counts, date of diagnosis, opportunistic infections) from this cohort of women, including information on experiences with HIV care and PMTCT care in prior pregnancies and whether having earlier pregnancies with HIV-negative versus HIV-

positive infants has any role in re-entry and retention in PMTCT programs.

All women interviewed had overcome barriers and were participating in a PMTCT program, so the information is biased towards women that can successfully navigate the system to access and adhere to care. Different information on barriers and facilitators would likely be obtained from interviewing women in the community who did not present for care during pregnancy or postpartum. The role of partner status (HIV-infected or uninfected) could also be a factor in uptake and retention in care that could not be explained in this study due to lack of partner information.

All women were interviewed near the location where they came to receive their PMTCT care, and as a result, there could be a bias that these women were less honest about negative experiences in care, for fear of this information being revealed to providers. In addition, we recognize that there may be cultural biases in this setting in Malawi that could have led women to be more likely to tell interviewers what they think the interviewers and the hospital providers would want to hear about barriers and facilitators to care, rather than their true opinion. It will also be important to note that this study represents a small region of Malawi and may not be generalizable to different communities.

Conclusion

PMTCT is a critically important strategy for decreasing HIV infections in Malawi. In order to increase uptake and adherence to care for HIV-infected women, programs will need to address barriers to care and build upon facilitators that may motivate and retain women. This is increasingly true given the transition to Option B+ for PMTCT, in which women are being initiated on ART during pregnancy and continued for life. This new policy has led to a decentralization of ART in Malawi, but significant barriers including transportation to and from clinics, stigma, and provider attitudes toward HIV-infected pregnant women must still be addressed to optimize outcomes in this program. Implementing programs and adopting strategies that facilitate care, such as improved education for women and

partners, adjunctive nutrition and food support, increased use of support groups, and community work on stigma reduction should be considered alongside the Option B+ rollout.

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Contribution of Authors

Ngozi Iroezi: Conceived study with team. Created interview instruments, performed interviews with Malawian collaborators, contributed to data analysis and performed primary writing of the manuscript. Deborah Mindry: Lead in study design. Created interview instruments, primary lead in qualitative data analysis, contributed to writing of the manuscript. Paul Kawale: Co-lead in study design. Organized the work in Malawi, oversaw interviews and study team, contributed to data analysis and writing of the manuscript. Grace Chikowi: Performed interviews, helped with translations, contributed to data analysis and editing of the manuscript. Perry Jansen: Provided input on interview instruments, data analysis, and writing/editing of the manuscript. Risa M. Hoffman: Co-lead in conceiving and designing the project. Oversaw all aspects of the project, helped to create interview instruments, contributed to data analysis, took a lead role in writing and editing the manuscript.

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